

Families of Individuals with Special Needs
Spring 2005

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Office Hours: Monday 11:30 - 1:00 pm and Tuesday 1 - 3 pm

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Required Text:

Berry, J. O., & Hardman, M. L. (1998). *Lifespan perspectives on the family and disability*.
Boston: Allyn and Bacon.

Remaining course readings are on e-reserves or can be found online on the Jackson library web page.

Teachers Academy Conceptual Framework Mission Statement: *The mission of professional education at UNCG is to prepare and support the professional development of caring, collaborative, and competent educators who work in diverse settings. This mission is carried out in an environment that nurtures the active engagement of all participants, values individual as well as cultural diversity and recognizes the importance of reflection and integration of theory and practice. UNCG's professional education programs are guided by shared commitments to: (a) equity and excellence in teaching, research, and service; (b) professional integrity and ethical deliberation in dealing with students and colleagues (university-based, school-based, and community-based); (c) the construction of a professional knowledge base through collaboration and collegiality; and (d) the dissemination of professional knowledge, skills and dispositions through the preparation and continuing professional development of teachers, principals and other school personnel.*

Goals and Objectives (Identification of INTASC standards and Core Competencies required for Advanced Licensure listed in parentheses).

By the end of the semester students will:

1. Understand the major theoretical approaches to family systems, family stress and coping, and social support that come from the literature on family development (Core competency 1).
2. Demonstrate the ability to critique and synthesize the current research on families with children with disabilities (Core competency 1).
3. Increase their knowledge of the social, emotional, and economic issues for family members

when one member of the family has a disability and how these issues change over the course of development.

4. Be able to critically analyze and synthesize the influences of culture and diversity on families with children with disabilities.

5. Demonstrate their knowledge of the major models of intervention and coping strategies, and recognize their implications for families.

6. Apply their knowledge of models to case studies of families who have a child with a disability and integrate the information presented in the course with other practical and applied experiences (INTASC 10; Core competency 2).

7. Develop and refine skills in oral and written communication and in the use of technology in presentations (INTASC 6).

Class Policies and Organization

The class meets on Tuesdays from 4 to 6:50 pm. Attendance is required and if an absence is anticipated, advance notification is required. Students are expected to follow the UNCG Honor Code. UNCG's Academic Integrity Policy can be found at <http://studentconduct.uncg.edu/policy/academicintegrity/>. Students must follow APA guidelines for properly citing written work and ideas from other authors. Failure to properly cite an author's work will be considered plagiarism and will result in disciplinary action as defined by university policies. Please be sure to ask me if you have any questions about this matter before you turn in any written work. Late papers are discouraged. If there is a medical or family emergency that prevents you from turning in a paper on time, let me know as soon as possible. In general, late papers will have points deducted from the grade.

Class Requirements

1. *Class readings and participation* - Be prepared each class session to participate in class discussion on all of the assigned readings. (15 points possible).

2. *Class attendance* - It is expected that students will attend all class sessions. Please notify me if you will not be in class. (15 points possible).

3. *Family Paper* - Each student will be required to write a 15-20 page paper on a topic that is of interest to you that is related to this course. The paper may be a critical review of empirical research, an evaluation of professional practices, an analysis of a theoretical, historical, or conceptual issue, or any other careful examination of a topic relevant to the focus of the course. I have provided a list of examples of paper topics below. Each paper should be based on research and must incorporate a theoretical perspective(s) or model(s). Please be prepared to discuss your ideas for your paper on February 8th. On March 15th you will be required to turn in an outline and present your idea to the class for feedback and suggestions. Your outline may be in point form, but should contain the main sections of your paper and a beginning reference list (at least 10 references). The final paper is due Friday, April 29th at 9 am and each student will present his/her paper on either April 26th or May 3rd using PowerPoint. Papers should all follow APA format. More information on this paper will be discussed in class (Possible points: 90 points for paper (includes 10 for outline) and 20 points for the presentation).

Examples of Paper Topics:

- Prenatal diagnosis and/or high-risk births on childbearing plans.
- An analysis of NICU transition programs for families
- Research on characteristics/needs/unique stressors of families with children from any particular diagnostic group (e.g. Autism, LD, Cerebral Palsy, Fetal Alcohol Syndrome, Down Syndrome, etc.)
- Chronic illness and/or death of a child and its impact/relationship to families
- Genetic counseling/technology and its impact on families
- Impact of poverty on family coping and resiliency
- Parent advocacy and support organizations
- Sibling support/stress/responsibilities/benefits
- Influence of children with special needs on parental/grandparental relationships
- Issues of culture/diversity for families with a child with a disability

4. *Self-Selected Assignments* - You may choose to do any of the follow assignments during the semester. Each assignment is worth various points and each student may complete assignments that total up to 100 possible points. Please note that some choices may be selected more than once while others may be completed only one time. You may complete any combination of the assignments below, according the guidelines provided, but you may only complete assignments that total to 100 possible points.

- Reactions to Assigned Readings - As many as two times during the semester you may write a reaction paper to the readings assigned for class. This paper should be 2 - 4 pages (double spaced) and cover information on all the required readings assigned for class. I am interested in your thoughts, reactions, questions, contentions, etc. related the articles or chapters, not a summary of the content. Use this as an opportunity to comment on, criticize, amplify, or take issue with aspects of the readings that you found particularly thought provoking or valuable. Reaction papers are due on the day of the readings. (10 points).
- Article/Chapter Critique and Presentation - You may choose to critique and present up to two articles/chapters during the semester. The articles or chapters may come from the assigned reading list (but not the case studies or your required text) or a pre-approved article. A 3 - 4 page paper (double spaced) must be handed in on the day when the article is presented. For this paper you should briefly summarize the article or chapter and then critique its value. The summary portion should be no more than half your paper. Think about what contribution the written work is making to the literature, the soundness of the piece (e.g. empirically or theoretically), and what implications this may have for researchers, practitioners, and/or parents. The in-class presentations should be about 10 minutes, should use PowerPoint, and should end with discussion questions that the class can respond to. You must sign up for an article at least two weeks before the in-class presentation. Please note that only one student may critique each article/chapter. (20 points possible for each article/chapter critique and presentation).

- Reaction to a parent or professional panel - You may choose to react to up to two of the parent or professional panels that come to class over the semester. In this reaction paper please summarize what you learned from the parents and how this connects (or does not connect) with your course readings or other literature you have read. Your reaction should be 2 - 4 pages, double-spaced and must be turned in the week after the panel presents. (10 points possible).
- Critical review of a media portrayal (e.g. movie, play, book) of families with a member(s) who has a special need. Once during the semester you may review and critique some form of media that portrays families and children with special needs. This paper should be 3 to 4 pages (double-spaced) and should review the content of the movie/book/play etc. and then critique it. In your paper, use relevant literature to support your critiques. All media must be pre-approved. The paper will be accepted any time during the semester up until April 19th (20 points possible).
- Reaction to an applied experience - Throughout the semester we will provide you with opportunities to meet with parents of children with disabilities and professionals who work with them. You may write a reaction paper related to any of these experiences (up to two during the semester). Examples may include attending a sibshop, spending an evening with a family, interviewing a family, participating in a home visit with an early interventionist, etc. Each paper should be 2 to 3 pages (double spaced) and should describe your experience and then link this experience to the theoretical and empirical readings you are doing for this course. Papers must be turned in one week after the experience (up to April 19th) (10 points possible).
- Web site list - Once during the semester you may develop a list of web sites (at least 10) that are relevant and useful for families with children with disabilities or professionals. In this list, please give the name of the site, the sponsoring agency/company, and then briefly describe (3-+ sentences) the purpose of the web site and the intended audience (e.g. parents, grandparents, siblings, professionals). Please provide a brief critique (3 - + sentences) of the positive and negative aspects of each site. Web site papers may be turned in any time up until April 26th (5 points possible).
- Creative Expression - Once during the semester you may share with the class a new creative piece of work that you have written or produced that relates to children with disabilities and/or their families. Examples of creative pieces might include an original poem, song, painting, dance, or sculpture. Each creative expression must be shared with the class on or before April 19th. Please confirm the date for your presentation with the instructors. (5 possible points).
- Virtual Family Reaction on Blackboard - Up to five times over the course of the semester you may react to your virtual family with other members of the class. The details of your virtual family will be discussed during class. In your reaction/discussion on Blackboard we are looking for your thoughts related to this experience as well as connections to what we have been discussing in class. You will receive points based upon the quality and depth of your

discussion. It is expected that each time you will react to both your own virtual family as well as respond to one other student from another virtual family. Discussion may occur up until April 26th. (5 points possible).

Please note that all written assignments should follow APA format and must adhere to the UNCG Honor Code.

Point Summary

Participation	15
Attendance	15
Family Paper	90
Family Paper Presentation	20
<u>Self-Selected Assignments</u>	<u>100</u>
Total: 240	

Course Grade

233 - 240	A+	192 - 198	B-
223 - 232	A	185 -191	C+
216 - 222	A-	175 -184	C
209 -215	B+	168 -174	C-
199 - 208	B		

HDF 660
Course Readings and Assignments

January 11 - Introduction - Disability and the Family Through Time

Berry and Hardman text - Chapter 1 (Disability and the family through time)

January 18- Family Theories Overview

Klein, D., & White, J. M. (1996). *Family Theories: An Introduction*. Thousand Oaks, CA: Sage Publications. Chapters 5 (The family development framework) & 6 (The systems framework). [e-reserves]

Berry and Hardman text - Chapter 2 (The family as an interactive unit) and Chapter 5 (The family within the community and broader social environment).

January 25 - Family Stress and Coping - Overview of models and theories

Berry and Hardman text - chapter 4 (Stress, coping, and family support)

McKenry, P. C., & Price, S. J. (2000). Families coping with problems and change: A conceptual overview. In P. C. McKenry & S. J. Price (Eds.) *Families and change: Coping with stressful events and transitions* (pp. 1 – 21). CA: Sage Publications. [e-reserves]

McCubbin, H., Thompson, E., Thompson, A., & McCubbin, M. (1993). Family schema, paradigms, and paradigm shift. In A. P. Turnbull, et al. (Eds.), *Cognitive coping, families, and disability* (pp. 239- 255). Baltimore, MD: Paul H. Brooks Publishing Co. [e-reserves]

February 1 – Parental Stress and Coping

O'Halloran, J. M. (1993). Welcome to our family Casey Patrick. In A. P. Turnbull, et al. (Eds.), *Cognitive coping, families, and disability* (pp. 19-29). Baltimore, MD: Paul H. Brooks Publishing Co. [e-reserves]

Peterson, G. W., & Mathieson, K. (2000). Understanding parental stress: A family perspective. In P. C. McKenry & S. J. Price (Eds.) *Families and change: Coping with stressful events and transitions* (pp. 71- 93). CA: Sage Publications. [e-reserves]

Judge, S. L. (1998). Parental coping strategies and strengths in families of young children with disabilities. *Family Relations*, 47, 263-268. (available online)

Stainton, T., & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual & Developmental Disability*, 23(1), 56-70. (available online)

Optional Reading:

Lessenberry, B. M., & Rehfeldt, R. A. (2004). Evaluating stress levels of parents of children with disabilities. *Exceptional Children*, 70(2), 231-244. (available online)

February 8 - Family Characteristics and Systems

Paper topic discussed in class

Turnbull, A., & Turnbull R. (2001). *Families, professionals, and exceptionality, fourth edition*. NJ: Merrill, pp. 84-104 (Chapter 5 - Family Characteristics). [e-reserves]

Volhs, J. (1993). On belonging: A place to stand, a gift to give. In A. P. Turnbull, et al. (Eds.), *Cognitive coping, families, and disability* (pp. 51-66). Baltimore, MD: Paul H. Brooks Publishing Co. [e-reserves]

Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: A qualitative inquiry. *Mental Retardation*, 41(5), 313-328. (available online)

Jackson, C. W., & Turnbull, A. (2004). Impact of deafness on family life: A review of the literature. *Topics in Early Childhood Special Education*, 24(1), 15-29. (available online)

Van Hooste, A., & Maes, B. (2003). Family factors in the early development of children with Down Syndrome. *Journal of Early Intervention*, 25(4), 296-309. [e-reserves]

Optional Reading:

Glidden, L. M., & Schoolcraft, S. A. (2003). Depression: Its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disability Research*, 47(4), 250-263. (available online)

February 15 - Culture and Diversity - part I – Online Class session

Diversity/Multicultural module – CENTeR (<http://center.uncg.edu>)

February 22 - Culture and Diversity - part II

McWilliam, P. J. (2000). *Lives in progress: Case stories in early intervention* (pp. 211- 222; La Maestra). Baltimore, MD: Paul Brookes Publishing. [e-reserves]

Murry, V. M. (2000). Challenges and life experiences of black American families. In P. C. McKenry & S. J. Price (Eds.), *Families and change: Coping with stressful events and transitions* (pp. 333-358). CA: Sage Publications. [e-reserves]

Balcazar, H., & Qian, Z. (2000). Immigrant families and sources of stress. In P. C. McKenry & S. J. Price (Eds.) *Families and change: Coping with stressful events and transitions* (pp. 359-377). CA: Sage Publications. [e-reserves]

Lee, H., Ostrosky, M. M., Bennett, T., & Fowler, S. A. (2003). Perspectives of early intervention professionals about culturally-appropriate practices. *Journal of Early Intervention, 25*(4), 281-295. [e-reserves]

Optional Reading:

Lai, Y., & Ishiyama, F. I. (2004). Involvement of immigrant Chinese Canadian mothers of children with disabilities. *Exceptional Children, 71*(1), 97-108. (available online)

March 1 - Families: Day to Day

Berry and Hardman text - Chapter 3 (Families: Day to day and across the lifespan)

Lukemeyer, A., Meyer, M. K., & Smeeding, T. (2000). Expensive children in poor families: Out-of-pocket expenditures for the care of disabled and chronically ill children in welfare families. *Journal of Marriage and the Family, 62*, 399-415. (available online)

Turnbull, A. P., Pereira, L., & Blue-Banning, M. J. (1999). Parents' facilitation of friendships between their children with a disability and friends without a disability. *The Journal of the Association for Persons with Severe Handicaps, 24*(2), 85-99. (available online)

Buysse, V., Goldman, B. D., Skinner, M. (2002). Setting effects on friendship formation among young children with and without disabilities. *Exceptional Children, 68*(4), 503-517. (available online).

Optional Reading:

Cuskelly, M., Pulman, L., & Hayes, A. (1998). Parenting and employment decisions of parents with a preschool child with a disability. *Journal of Intellectual and Developmental Disability, 23*(4), 319-333. (available online).

March 8 - Spring Break - No Class

March 15 - Families Over the Life Course – Early Childhood Years

Paper Outline Due

Berry and Hardman text - Chapter 7 (Families and the early childhood years)

McWilliam, P. J. (2000). *Lives in progress: Case stories in early intervention* (pp. 223-235; Heaven's Glory). Baltimore, MD: Paul Brookes Publishing. [e-reserves]

Tien, C. L., Peterson, C. A., & Shelley, M. C. (2002). Postdischarge service use by families of neonatal intensive care unit graduates. *Journal of Early Intervention, 25*(1), 42-57. [e-reserves]

Peterson, C. A., Wall, S., Raikes, H. A., Kisker, E. E., Swanson, M. E., Jerald, J., et al. (2004). Early Head Start: Identifying and serving children with disabilities. *Topics in Early Childhood Special Education, 24*(2), 76-88. (available online)

Rafferty, Y., Boettcher, C., & Griffin, K. W. (2001). Benefits and risks of reverse inclusion for preschoolers with and without disabilities: Parents' perspectives. *Journal of Early Intervention, 24*(4), 266-286. [e-reserves]

Optional Readings:

Cross, A. F., Traub, E. K., Hutter-Pishgahi, L., & Shelton, G. (2004). Elements for successful inclusion for children with significant disabilities. *Topics in Early Childhood Special Education, 24*(3), 169-183. (available online)

Trivette, C. M., & Dunst, C. J. (2004). Evaluating family-based practices: Parenting Experiences Scale. *Young Exceptional Children, 7*(3), 12-19. {e-reserves; not for article critique}

Banks, R. A., Santos, R. M., & Roof, V. (2003). Discovering family concerns, priorities, and resources: Sensitive family information gathering. *Young Exceptional Children, 6*(2), 11-19. {e-reserves; not for article critique}

March 22 - Families Over the Life Course – School Age

Berry and Hardman text - Chapter 8 (Families and schools)

Bower, A. M., & Hayes, A. (1998). Mothering in families with and without a child with a disability. *International Journal of Disability, Development, and Education, 45*(3), 313-322. (available online)

Martin, J., Marshall, L. H., & Sale, P. (2004). A 3-year study of middle, junior high, and high school IEP meetings. *Exceptional Children, 70*(3), 285-297. (available online)

Kolb, S. M., & Hanley-Maxwell, C. (2003). Critical social skills for adolescents with high incidence disabilities: Parental perspectives. *Exceptional Children, 69*(2), 163-179. (available online)

Optional Reading:

Grigal, M., Neubert, D. A., Moon, M. S., & Graham, S. (2003). Self-determination for students with disabilities: Views of parents and teachers. *Exceptional Children, 70*(1), 97-112. (available online)

March 29 - Families Over the Life Course – Adult Years

Berry and Hardman text - Chapter 9 (Families and the transition from school to adult life) & 10 (Families and the adult years)

Schulz, J. B. (1993). Heroes in disguise. In A. P. Turnbull, et al. (Eds.), *Cognitive coping, families, and disability*. Baltimore, MD: Paul H. Brooks Publishing Co. pp. 31 - 41. [e-reserves]

Krauss, M. & Seltzer, M. (1993). Coping strategies among older mothers of adults with retardation: A life-span developmental perspective. In A. P. Turnbull, et al. (Eds.), *Cognitive coping, families, and disability*. Baltimore, MD: Paul H. Brooks Publishing Co. pp. 173-182. [e-reserves]

Llewellyn, G., Gething, L., Kendig, H., & Cant, R. (2004). Older parent caregivers' engagement with the service system. *American Journal on Mental Retardation*, 109(5), 379-396. (available online).

Optional Reading:

Bennett, T., & DeLuca, D. A. (1996). Families of children with disabilities: Positive adaptation across the life cycle. *Social Work in Education*, 18(1), 31-45. (available online)

April 5 - Siblings and Extended Family Members

McWilliam, P. J. (2000). *Lives in progress: Case stories in early intervention* (pp. 39-45; Absent Mother). Baltimore, MD: Paul Brookes Publishing. [e-reserves]

Turnbull, A., & Turnbull, R. (2001). *Families, professionals, and exceptionality, fourth edition*. NJ: Merrill, 84-104 (Chapter 6 - Family Interaction). [e-reserves]

Stoneman, Z., & Brody, G. H. (1993). Sibling relations in the family context. In Z. Stoneman, & P. Berman (Eds.) *The effects of mental retardation, disability, and illness on sibling relationships: Research, issues, and challenges*. Baltimore, MD: Paul H. Brookes Publishing Co., pp. 3-30. [e-reserves]

Cuskelly, M., & Gunn, P. (2003). Sibling relationships of children with Down syndrome: Perspectives of mothers, fathers, and siblings. *American Journal on Mental Retardation*, 108(4), 234-244. (available online).

McCallion, P., Janicki, M. P., & Kolomer, S. R. (2004). Controlled evaluation of support groups for grandparent caregivers of children with developmental disabilities and delays. *American Journal on Mental Retardation*, 109(5), 352-361. (available online).

Optional Reading:

Weisner, T. S. (1993). Ethnographic and ecocultural perspectives on sibling relationships. In Z. Stoneman, & P. Berman (Eds.) *The effects of mental retardation, disability, and illness on sibling relationships: Research, issues, and challenges*. Baltimore, MD: Paul H. Brookes Publishing Co., pp. 51-83. [e-reserves]

April 12 - Communicating and Working with Families

Berry and Hardman text - Chapter 6 (Communicating and collaborating with families)

Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children*, 70(2), 167-184. (available online).

King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Pediatric Psychology*, 24(1), 41-53. (available online)

Brady, S. J., Peters, D. L., Gamel-McCormick, M., & Venuto, N. (2004). Types and patterns of professional-family talk in home-based early intervention. *Journal of Early Intervention*, 26(2), 146-159. [e-reserves]

Optional Reading:

Quinn, P. (1999). Supporting and encouraging father involvement in families of children who have a disability. *Child and Adolescent Social Work Journal*, 16(6), 439-454. (available online).

April 19 - Overview & Next Steps for the Field

Kalyanpur, M. & Harry, B. (1999). The role of professional expertise and language in the treatment of disability. In M. Kalyanpur (Ed.) *Culture in special education: Building reciprocal family-professional relationships*. Baltimore, MD: Paul H. Brookes, 47-75. [e-reserves]

Yau, M. K., & Li-Tsang, C. W. P. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. *British Journal of Developmental Disabilities*, 45, 38-51. [e-reserves]

April 26 – Paper presentations

April 29 – Final papers due by 9 am

May 3 - Paper presentations

Please note that additional readings may be assigned during the semester.